

REVIEW OF NIH'S HEALTHY WEB SITES

Mr. Ron Sleyo

MR. SLEYO: -- Welcome and good morning. My name is Ron Sleyo. I am with the National Institute of Diabetes and Digestive and Kidney Diseases at the National Institutes of Health, more familiarly known as the NIH.

In a few moments we are going to be looking at the kinds of health information available at the National Institutes of Health and on several popular nongovernment and commercial health Web sites.

Before I begin my review on the NIH's Healthy Web Sites, I would like to briefly introduce you to the NIH environment. Founded in 1887, the National Institutes of Health began as a one room laboratory of hygiene with a total research budget of only \$300.

Today, the NIH campus is comprised of 25 separate research institutes and centers with 75 buildings situated on more than 300 acres. The NIH research budget last year was over \$17.6 billion.

The NIH is one of eight health agencies of the Public Health Service, which in turn is part of the Department of Health and Human Services.

The NIH mission is to uncover new knowledge that will lead to better health for everyone. It works toward that mission by conducting biomedical research in its own laboratories and by supporting, through contracts and grants, the research of nonfederal scientists in universities, medical schools, hospitals, and research institutes throughout the country and abroad.

The NIH, fortunately for the benefit of you and me, fosters communication of medical information through its libraries of online health reports, factsheets, information directories and research publications.

This morning you will have an opportunity to look at a small sample, a needle in the health haystack so to speak, on health information at the NIH and on other nongovernment health Web sites. We will visit in a few moments NIH's healthy Web sites with information on aging, breast cancer, diabetes, nutrition and obesity, depression, high blood cholesterol, and osteoarthritis, and we will look briefly at other nongovernment sources of health information such as the Mayo Clinic, HealthTouch, and the American Medical Association.

The sites we'll be visiting today are but a few of the thousands of health Web sites on the Internet. Rather than trying to visit all of them, with little success, I am going to show you instead how to find health information of particular value to you or a member of your family.

Let's begin our Internet healthy Web site journey with a familiar story line opening. Once upon a time ... we relied solely on our own personal physician to help us manage our health care needs. Today many of us are more likely to access the Internet to get information about what ails us or a member of our family.

The Internet has turned health care into a hands-on affair. For example, with just a few mouse clicks, we can navigate our way through a vast array of health sites, medical journals, and online support groups for virtually any medical problem.

There is an abundance of riches that awaits us in seeking health information via the Internet and some fool's gold as well.

The question today is not what kinds of health information are online but what is not online. Let's look at recent statistics.

There is estimated to be over 70,000 health sites on the World Wide Web. Some projections go as high as 200,000. And over 120 million people searching these sites for health information.

With such a staggering amount of online health information, how do we differentiate between good and reliable health information -- and the not-so-good, and unreliable?

Unfortunately, there is no sure fire way of telling whether a site is or is not worthwhile, but there are signposts to guide us in finding our way to the most reliable health information on the Internet.

The first sign post: The Internet is often considered the last frontier where free speech reigns. For now, anyone can post anything online, whether or not it is true. The same anonymity that cloaks you and me in seeking health information can also cloak virtual quacks and full-blown rascals with bad and sometimes dangerous advice on the Internet. Even individuals whose motives are genuine may have inaccurate information. So whom do you trust?

The first rule in gathering health information on the Internet is to know who is putting out the information. Look for reputable sources such as the National Institutes of Health, medical schools, health care institutions, professional medical associations such as the American Heart Association, the Diabetes Association, and familiar national disease center organizations such as the American Cancer Society. Their online health information is reviewed by scientific and advisory boards before it gets to you.

Other government agencies such as the Department of Health and Human Services, the Centers for Disease Control and Prevention, the National Clearing House

for Alcohol and Drug Information, and the Agency for Health Care Research and Quality, just to name a few, are also considered highly reliable sources of public health information. Their factsheets, handouts, brochures and publications on health are reviewed by scientific boards before public consumption.

The same rules apply when searching for health information on commercial Web sites. Look for code of conduct endorsements by independent health foundations such as Health on the Net Foundation. These foundations give a stamp of approval on the reliability, authority, confidentiality, and sponsorship of health information on health Web sites.

On the screen (slide 7) you are looking at several code of conduct principles from the Health on the Net Foundation. The HONCODE emblem, which we will see later, indicates that the health and medical information on the Web site has been reviewed by medically trained and qualified professionals -- and that the site clearly identifies sponsorship by commercial and noncommercial organizations that have contributed funding, services, or materials for the site.

This last principle segues appropriately to my final point. When viewing health Web sites, look to see if there is a potential conflict of interest such as a commercial firm promoting its own products or contributing to the funding or services for the site.

These are some of the sign posts to watch out for when seeking health information on the Internet. With that in mind, here are some healthy Web sites worth visiting.

The information you are viewing on the screen is available in the packet of material you already have on NIH Healthy Web Sites, so it is not necessary for you to write down the address of each Web site that we will be looking at this morning. First, let's quickly browse the handout and get an idea of how the sections are put together. The handout on NIH Healthy Web Sites can be viewed electronically at: <http://www.recgov.org/nih-hr/nih-community.html> or on NIH's Office of Community Liaison Web site.

The NIH handout is divided into several sections. In the first section you will find health and medical information that is NIH-wide. The second section focuses on health and medical information on individual institute Web sites. The next section deals with our afternoon program, "Kids Health Information at the NIH."

The last section on the handout pertains to nonfederal health and medical information which includes popular commercial health sites for finding information on clinical trials, prescription drugs, medical dictionaries, video tours of the human anatomy, and women's health resources.

Let's go back to the first section of the handout dealing with the NIH health sites. When visiting the NIH, you will find health information ranging from the treatment of mild allergies to the latest studies on rare diseases. You will also find in searching for health information at the NIH that the amount of information online is staggering. There are millions of health Web pages and hundreds of Web sites to choose from -- so where do you start?

There are three principal sources (methods, techniques, protocols) that we can use in finding health information at the NIH. Let's use the first source in looking for health information, for example, on rheumatoid arthritis. We will begin our search using the NIH 2000 Health Information Index.

The Health Information Index site on the screen: Health Information Index is a subject word guide to diseases and conditions currently under investigation at the NIH. The index will identify for you the research institute responsible for research in your area of interest.

For example, we are looking for information on rheumatoid arthritis. We will go to the index and look for rheumatoid arthritis, and as we cursor down the page you can see the multitude of other research protocols at the NIH.

We'll stop at rheumatoid arthritis and look at some reference information. You'll see, next to rheumatoid arthritis health information, the name of the Institute, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, conducting primary research in the area of rheumatoid arthritis diseases.

Now we are on the National Institute of Arthritis Musculoskeletal Skin Diseases Web site. We will go to their health information, their online brochures and medical publications. We can cursor down the page and find information on rheumatoid arthritis, but first let's browse and look at other health publications on this site. We'll see information on arthritis and exercise, arthritis pain, fibromyalgia, hip replacement, juvenile rheumatoid arthritis, knee problems, osteoporosis, and finally we get to our query on rheumatoid arthritis.

You will find, in the publication on rheumatoid arthritis, information such as the features of rheumatoid arthritis, how rheumatoid arthritis develops and progresses, occurrence and impact, searching for causes, diagnosing, and current research.

We also could have located this information by going directly to the National Institute of Arthritis, Musculoskeletal and Skin Diseases via their online address, <http://www.niams.nih.gov>. You will find that address at the bottom of your screen.

We will find I have listed for you, also, the Handbook on Rheumatoid Arthritis. If we click on that listing, the handbook automatically comes up.

The same principle -- that we used in finding information on rheumatoid arthritis can be used in finding any other health information that you are interested in. Let's look for information on lowering high blood pressure.

We will go to -- I should say we will go back to -- the 2000 NIH Health Information Index. We will look for information on high blood pressure. We will cursor down to that information and we will find the topic high blood pressure. After the topic, we have the institute primarily responsible for conducting and supporting research in that area: The National Heart, Blood and Lung Institute.

On the same page we can see we have the "Guide to Lowering High Blood Pressure" on their face page. You will note that it presents information on this topic to several different audiences. You have information for consumers, health professionals, community organizations, and media.

Like we did in the search for arthritis information, we could also go directly to the National Heart, Lung, and Blood Institute homepage. The address is at the bottom of the page.

If we do not know where to start our search for health information or are not quite sure which institute is principally responsible for conducting and supporting research for that particular disease, then we can go to the NIH search directory to find information on that topic.

The NIH search directory is a tool for finding when you are uncertain where to look for health information on a particular topic. Let's look for information on heart disease.

To get to their page, it's just matter of typing in the word "heart" to find the documents at the NIH that pertain to heart disease. Since we're being intentionally unspecific as to which aspect of heart disease we are interested in finding, you'll note on the top of the page that the word "heart" is found in 10,344 online documents at the NIH.

In using the NIH search directory expect to find a large number of documents since we did not qualify our search to a specific area of heart disease. If we had qualified our search using modifiers such as "and," "or," or "not" to narrow our search -- for example, if we used the following combination of words -- heart and congestive -- we would find information specifically pertaining to congestive heart failure, much limited amount of information compared to the 10,344 documents on heart disease.

The idea presented here is that you can use a search tool on a Web site such as the NIH Search Directory to refine your search results.

When all else fails, if you are unable to find what you are looking for through the resources that I have mentioned -- the NIH 2000 Health Information, individual Institute health sites, or the NIH search engine -- then the next best thing to do is go to National Information Center Web site.

The National Information Center Web site is a health information referral service. It puts you in touch with health professionals and finds information on health questions and organizations to contact. This organization has toll free numbers, which you can use to find information in a particular area of research, and it lists those areas of research.

You could also call directly any information office at the NIH and speak with a representative who will help you find specific health information -- that information is available in the handout on NIH Healthy Web Sites.

Now let's move forward and look at other Web sites that provide health information. Let's look at the collection of the most requested NIH publications listed by each Institute at the NIH.

We can view information at this site by either key word or Institute. What we see in front of us is information listed by Institute. Again you can see the wealth of online information available at your finger tips.

NIH also has its own daily radio broadcast that provides up-to-date information on current health research. What we'll do is briefly listen to one on stroke to give you an idea of what is available. As it loads up, these are short reports and they are --

(Playing Radio Recording.)

MR. SLEYO: The text versions of these audio reports are also available at the above address.

(Recording continues.)

MR. SLEYO: That report on stroke will go on for a few more minutes. Let's move forward so we can look at other health Web sites.

What I would like to also show you very quickly is one of the premiere Web sites at the NIH, that is, MEDLINE PLUS.

You will find at MEDLINE PLUS information on generic and brand-name drugs, medical dictionaries, medical encyclopedias, hospitals, physicians and health professional

directories, consumer health guides, and clinical research studies being conducted by the NIH.

If we are looking, for example information on lowering cholesterol and the triglycerides, we'll see that the medication being prescribed is lipitor. We can click on their drug index and find information on lipitor.

What we will find when we look at information on lipitor is a description of drugs, the risks, the proper use of the drugs, precaution when using the drugs, and side effects from the medication. Also, MEDLINE PLUS has medical dictionaries and hospitals and professional directories, and it is one of the most popular sites at the NIH.

Let's look quickly at other popular and nongovernment health Web sites such as the Mayo Clinic, which I have listed in your handout on NIH Healthy Web sites. You'll see that their information also includes a daily news report called "Health Watch Line." They have a direct link to physicians and nutritionists at their site that can help answer a wide range of questions in that particular area.

They also have, which I would like to show you, at the bottom of the page a code of conduct symbol that we talked about earlier. This symbol gives a stamp of approval on the reliability of health information on this site.

That is about all the time I have so in closing here are a few final observations.

The Internet is not a replacement for your health care provider, regardless of how reliable the source. But there does reside a vast accumulation of information from experts, patients, doctors, researchers and teachers. Used wisely, the Internet can help you make informed choices about your health care and treatment options.

The NIH Healthy Web Sites presentation was intended to give you an opportunity to assess the value of the Internet in terms of its benefits to you.

You will find in the material of information you have today the handout on NIH Healthy Web Sites. Use the handout to add new sites as you discover them.

This concludes my remarks on Internet access to health information. If you have any specific questions, please feel free to ask me or the special NIH Web volunteers with us today. These volunteers are here to help you find health information of value to you. You will recognize them by their name plate.

Thank you and enjoy the rest of the day.

(Applause.)

MR. SLEYO: Yes?

(Inaudible—Someone not at a microphone asks a question).

MR. SLEYO: This afternoon we have a program for Kid's Healthy Web Sites. I am not going to repeat this one but I will present again at the Kids sites information at 1:30 --

(Inaudible—Someone not at a microphone asks a question).

MR. SLEYO: Okay. Glad you thought it was informative. Yes maybe next year ...

(Inaudible—Someone not at a microphone asks a question).

MR. SLEYO: Okay. It is 1:30.

(Inaudible—Someone not at a microphone makes a comment).

MR. SLEYO: Thanks.

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